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ILAE Commission Report

Restrictions for Children with Epilepsy

Commission of Pediatrics of the ILAE

If a child has epilepsy, families and caregivers understandably worry about seizure-related injuries. Such concerns frequently limit the child's activities and result in restrictions that may lead to undesirable behavioral and psychological consequences with major adverse effects on the child's quality of life and psychosocial well-being.

In reality, childhood itself is filled with inherent risks, and children with epilepsy are at only minimally greater risk than their peers who do not have seizures (1). It is not possible to provide guidelines that can be applied to *all* children with epilepsy. However, several principles form the basis for developing recommendations about limitations:

1. Decisions should balance the need to encourage the child's continued self-development in terms of knowledge, independence, and self-confidence that will realize his or her eventual full potential against the need to protect the child and others from physical and emotional injury.
2. Restrictions, when necessary, should be tempered by common sense.
3. Medical personnel should be facilitators and provide the means for families to be creative in appropriately individualizing limitations tailored to their child's needs.

NEED FOR RESTRICTIONS

There are three main reasons to restrict the activities of children with epilepsy. First is the perceived risk of physical injury to the child related to a seizure, such as falls, burns, cuts and abrasions, broken bones or teeth, and shoulder dislocation. Second is limitation of exposure to events or circumstances that can trigger seizures in children, such as photic stimulation, lack of sleep, alcohol, and fever. Last, restrictions may be considered in exceptional circumstances to avoid potential emotional injury.

For some children, restrictions should be time-limited,

as in the following situations: (a) for 2–3 months after a first untreated seizure; (b) after treatment is initiated and until it can be determined that further seizures are unlikely, and (c) for a few months after antiepileptic drugs (AEDs) have been discontinued. Restrictions may be required indefinitely in children who have persistent recurrent seizures uncontrolled by treatment. A few such children have epilepsy syndromes that progress and evolve. In such cases, consideration of the necessity for limitations may require modification over time.

FACTORS AFFECTING DECISIONS ABOUT RESTRICTIONS

The following issues are relevant to decisions concerning restrictions.

Age of the child

Permitted activities should be age appropriate for any child, matched to temperament and level of understanding. For children aged <8 years, restrictions are generally considered "rules." Older children can usually understand the need for and the importance of limitations, and their agreement should be sought in establishing individualized restraints that usually need apply for only a limited time.

Seizure type

Just as first aid for seizures varies according to seizure type, so do restrictions and limitations. Seizures that do not cause loss of consciousness or that occur only during sleep require few changes in lifestyle. In contrast, seizures associated with impaired consciousness place children at higher risk of injuries.

Seizure frequency

Children with infrequent seizures may not need any restrictions. Indeed, if the child has had a ≥ 1 -year seizure-free interval, it is reasonable to discontinue most limitations. On the other hand, children who have very frequent absence, myoclonic, atonic, or tonic seizures, and in those with newly diagnosed epilepsy, appropriate restrictions are required until adequate seizure control has been established.

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Timing and location of seizures

Some children have seizures only during sleep, a time when they are usually confined in soft places. Others have seizures that are provoked by flickering light, television, or video screen. Such circumstances may be avoidable, or their import may be limited, by having the child use sunglasses or close one eye. Occasionally post-ictal states will be prolonged and are a source of concern.

Compliance

The ability of the child to take AEDs regularly, and the responsibility for doing so, are also significant factors, particularly in adolescents and in families who cannot afford to purchase medication regularly.

Comorbid diagnoses

The presence of an additional diagnosis, such as a physical or mental handicap, may also be a confounding factor in determining the need for limitations.

POTENTIAL RESTRICTIONS

The following restrictions may be considered in individual children when the degree of risk from a seizure is weighed against the consequences of the restriction.

In the home

Younger children should never be left alone in the bath. Older children should be encouraged to use a shower and should be reminded not to lock the bathroom door. Loss of consciousness can lead to falls and drowning (2,3). Enveloping or potentially suffocating sleeping surfaces (waterbeds), bed covers, and pillows should be avoided, especially for infants and young children. Open fires, hot stoves or ovens, and stairs should be avoided.

With caregivers other than parents

The babysitter, personnel in daycare centers, and the school, and any persons responsible for the child should be informed of the seizure disorder. It is important that caregivers be acquainted with basic facts, issues, and precautions concerning the child's epilepsy. Caregivers often have fears that they will not recognize a seizure or be able to administer proper first aid if a seizure occurs.

The parents should provide all caregivers with a description of the child's seizures and information on first aid and when and whom to call if a seizure occurs. Caregivers should be reminded to react in a calm and matter-of-fact manner during seizures so that the child and any other children who may be present will respond with the least possible alarm and fear. After a seizure is over, the child is often confused and embarrassed and reassurance is needed.

If possible, the child should attend a regular school appropriate for his or her cognitive ability. The family or physician should inform the school doctor or nurse of the child's epilepsy and any relevant issues and precautions.

The child should be allowed to take part in all sports and extracurricular activities available in the school. Regular physical activity and proper study habits will not precipitate seizures.

Occasionally a child may be at high risk of status epilepticus. If a caregiver has been trained to manage the situation and administer rapid-acting AEDs such as rectal diazepam, restrictions may be less stringent. If the child is predictably incontinent during seizures, it may be wise to keep a change of clothing at school. In general, classmates should be informed of the child's epilepsy, particularly if seizures generalize or are otherwise highly visible. It often takes time for a family to accept the need to divulge their child's medical condition, but this should be encouraged.

Sports and recreational activities

Swimming, rowing, paddling, sailing

All children involved in water sports should always be under the watchful eye of an experienced and responsible swimmer (3). A buddy system is a good idea, and use of life jackets is prudent. The main questions to be asked are: "How old is the child?" "How frequent are the seizures?" and "How well is the child supervised?" The responses must then be considered in analyzing risks and benefits.

Climbing ropes, trees, cliffs (heights)

Risks involving heights require restrictions. It does not matter if the child has epilepsy; common sense prevails.

Biking, skating, rollerblading, skateboarding

It is wise for all children, not only those with epilepsy, to avoid busy streets. All children should wear helmets and padding, regardless of their tendency to have seizures. If seizures are uncontrolled or diagnosed very recently, biking, skating, rollerblading, and skateboarding initially should be limited.

Cross-country skiing, long-distance running, and other endurance sports

The effects of strenuous exercise are unlikely to increase the chance of a seizure. Training for the sports event will probably provide a good test of whether a seizure will occur.

Football, rugby, soccer, hockey (contact sports)

Minor head trauma is very unlikely to precipitate a seizure.

Scuba diving and sky diving

Scuba diving and sky diving are among the few activities that should be avoided.

Camping or spending the night with a friend

Just as at school or with sports and recreational activities, persons responsible for the care of a child with epilepsy should be aware of what the child's seizures

look like, how to administer appropriate first aid, and how to notify the family if the need arises.

Travel on airplanes or to areas with poor medical care

As long as there is access to medical care, no limitations on travel are necessary for children with epilepsy. Families should plan and anticipate what will be needed and what action will be taken if the child has a seizure. There may be times when common sense dictates that travel be restricted briefly or that rapid-acting AEDs be available for the family to administer.

Driving an automobile or other vehicle

Laws regarding driving restrictions vary from country to country. Some countries have no restrictions, provided the physician gives permission to drive; others require that a person with epilepsy be free of seizures for 3 months to 1 year.

Persons with active epilepsy should be warned of the risks associated with driving and this warning should be documented in writing. Patients who are noncompliant with their AED regimen should be prevented from driving and warned of the risks and lack of insurance coverage if an accident should occur.

Although laws vary, a person experiencing seizures as a result of physician-directed changes in medication generally need not stop driving if it is expected that resumption of the previous drug regimen will reestablish seizure control. However, discontinuation of medication poses a dilemma for both the physician and the driver. In appropriate patients, the risk of seizures recurring once

medication is discontinued is small, and if a seizure recurs it is most likely to do so the first 3–6 months after AED discontinuation. Generally, patients should not drive during this time period.

FUTURE DIRECTIONS: HOW CAN RESTRICTIONS BE MINIMIZED?

To minimize restrictions on children with epilepsy, community and family education must increase. Children should be encouraged to participate in activities that do not pose a threat of physical injury. Research is needed to identify and evaluate the appropriateness of restrictions and their proper duration. Finally, the impact of implementing appropriate restrictions should be evaluated in a controlled, scientific fashion.

Note: Commission Members: Professor Olivier Dulac, Chairman; Dr. Frank Besag; Professor Neil Buchanan; Professor Carole Camfield; Professor Bernardo Dalla Bernardina; Dr. Charlotte Dravet; Dr. Stella Maris Ferraro; Dr. Adalberto Gonzalez-Astiazaran; Dr. Gregory L. Holmes; Professor Maryse Lassonde; Professor Niall O'Donohoe; Professor Shunsuke Ohtahara; Dr. Igor M. Ravník; Dr. Willy Renier; and Dr. Joseph Roger.

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